Cogitare Enfermagem

ORIGINAL ARTICLE

PARENTAL BEREAVEMENT: EXPERIENCES OF THE NURSING STAFF IN NEONATAL INTENSIVE CARE

HIGHLIGHTS

1. Experiencing parental bereavement by nursing staff.
2. Professionals' attitudes towards bereavement.
3. Strategies based on empathy and humanization.
4. Contributions to the care of bereaved parents

Luciana de Carvalho Pires[1]
Regina Gema Santini Costenaro[1]
Maria Helena Gehlen[1]
Liliane Alves Pereira[1]
Camila Freitas Hausen[2]
Eliane Tatsch Neves[2]

ABSTRACT

Objective: to know the experience of the nursing team when acting in situations of parental bereavement in Neonatal Intensive Care. **Method:** qualitative study developed through semi-structured interviews from March to April 2021 with nursing professionals from a Neonatal Intensive Care Unit in Rio Grande do Sul, Brazil. The results were submitted to thematic content analysis. **Results:** The act of experiencing parental bereavement by the nursing staff involves sadness, helplessness, and suffering. Strategies faced at this moment are based on empathy and humanization. For the professionals, the knowledge to face the situation comes from their own experiences of loss in their personal and professional lives, from their strength and religiosity. **Conclusion:** it is expected that this study contributes to the practice of health professionals in assisting parents who experience the process of parental bereavement in neonatal intensive care.

DESCRIPTORS: Bereavement; Intensive Care Units, Neonatal Nursing; Neonatal Nursing; Parents.

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[1]Universidade Franciscana, Curso de Graduação em Enfermagem, Santa Maria, RS, Brasil.
[2]Universidade Federal de Santa Maria, Curso de Pós-graduação em Enfermagem, Santa Maria, RS, Brasil.

INTRODUCTION

Bereavement is made up of biological, psychological, and social factors that are intertwined with human beings in their losses throughout life[1]. The loss of a child is one of the worst pains that a human being can feel, because it is a reality not expected by those who gave birth to life. When the loss is of a newborn child, there is a tendency for the suffering, besides lasting a long time, to culminate in depression or other psychological problems[2].

To the process of losing a child, the concept of parental bereavement is attributed. The family experiences physical and existential emptiness, frustrating the plans they had for their child[1]. Neonatal death seems to be unacceptable in the face of advances in health care, especially in the context of the Neonatal Intensive Care Unit (NICU), being marked by great sadness and distress not only for parents and family members, but also for the health team[3].

Thus, it is necessary that the approach to the family in the process of parental bereavement at the NICU occurs as a team, considering that the family goes through phases such as anger, despair and sadness[4], and parents may present negative psychological symptoms in the period after the child's death, such as sadness, anxiety, and fear, which denotes the need for support strategies for people in the bereavement process[3]. Therefore, the approach to bereavement at the NICU is a universal, singular, complex, and multidisciplinary process[1].

In this context, nursing care for parental bereavement stands out as one of the family's needs. In this situation, the team must develop humanized care in a technological, delicate, and extremely sensitive environment, which requires skills and abilities for welcoming, bonding, and therapeutic communication[5].

This study had as its theoretical foundation the National Program for Humanization of Hospital Care (PNHAH- in Portuguese), which later became the National Humanization Policy (PNH- in Portuguese)[6]. This program foresees the action of putting into practice the principles of the Brazilian Unified Health System (SUS- in Portuguese) in the daily life of health services, bringing changes in the way of managing and caring. It was also based on Ordinance 198/GM, of February 13, 20047, which established the National Policy for Continuing Education in Health, because it is understood that, to deal with complex issues such as parental bereavement, it is necessary to train professionals, which is part of the institution's Continuing Education Policy.

Therefore, this study is justified by the importance of focusing attention on the nursing staff working at NICU regarding parental bereavement, as this is a delicate and sometimes veiled issue in the hospital environment. Thus, this study is relevant for providing more knowledge on the subject, contributing to the implementation of qualified nursing care in the approach to parental bereavement at the NICU by health professionals.

Therefore, the following research question was formulated: what are the experiences of the nursing team when dealing with parental bereavement in a Neonatal Intensive Care Unit? The objective was to know the experience of the nursing team when acting in situations of parental bereavement in Neonatal Intensive Care.

METHOD

Exploratory, descriptive research with a qualitative approach, which followed the description criteria of the Consolidated Criteria for Reporting Qualitative Research

(COREQ) guide. The study setting was a NICU of a University Hospital in the central region of Rio Grande do Sul (RS), Brazil. This hospital is a reference for high-risk pregnant women and children born at or below 36 weeks of pregnancy.

The nursing team at this hospital's NICU consists of 21 nurses and 40 nursing technicians, distributed in three shifts. Each of these professionals has a workload of 36 hours per week. Inclusion criteria were being a nurse or nursing technician working in a NICU and having experienced the parental bereavement approach at the NICU. Professionals who were away on medical certificate or on leave during the data collection period were excluded from the study. Thus, 26 professionals of the nursing team working at the NICU participated in this research, 17 nurses and nine nursing technicians.

Access to participants occurred through initial contact with the person responsible for the unit, who requested the work schedule of the nursing team professionals, and, through this, the professionals were contacted for the invitation. Upon acceptance, data was collected between March 23 and April 28, 2021, through semi-structured interviews, conducted by one of the authors of the study, and the average duration of the interviews was eight minutes. Data were collected at the NICU in a preserved room to avoid any disturbance to the unit's routine and at a time convenient to the participants.

The interviews were recorded with the interviewee's consent using a digital recorder. Afterwards, they were transcribed by the authors of the manuscript, thus making the analysis possible. Theoretical saturation[8] was used to close the data collection. The verbal accounts of the interviews were analyzed according to Bardin's content analysis methodology[9].

The verbal reports of the interviews were analyzed according to Bardin's content analysis methodology[9].

The research was approved by the Ethics in Research Committee of the respective institution under opinion number 4,594,095. To preserve the identity of the study participants, the speeches were coded with the letter "N" (Nurses) and the letter "NT" (Nursing technicians).

RESULTS

Twenty-six NICU professionals participated in the study, of which 17 (65.4%) were nurses and nine (34.6%) were nursing technicians. Of these, 25 (96.1%) were female, and one (3.9%) was male. The mean age of the participants was 38.5 years, with ages ranging from 28 to 52 years.

As for the level of education, 21 (80.8%) are postgraduates, three (11.5%) have higher education, and two (7.7%) have technical education. As for the time of graduation in nursing, the average was 15 years and six months. Regarding the time working in the NICU, the average was 10 years and six months.

Through the reading and analysis of the interviews, three categories were created, as follows: Sentiments related to the experience of parental bereavement"; "Experiencing nursing care in the face of parental bereavement"; and "Knowledge and beliefs about the experience of parental bereavement", which are presented below:

In the category "Feelings related to the experience of parental bereavement", it was observed, from the perception of the interviewed professionals, reports of feelings of sadness and impotence when acting in parental bereavement, not only in face of the frustrated expectations of parents regarding taking their child home, but also since professionals "put themselves" in the parents' shoes, imagining themselves in such a situation (of parental bereavement). Moreover, the feelings of sadness and helplessness were also mentioned

from a professional perspective, that is, because, as nursing professionals, they did not want to lose the patient.

[…] Sadness, anguish for that family [...], that created so many expectations with that child, unfortunately, they do not go home with her [...]. (N5)

[…] Impotence, sadness, because you end up putting yourself in the place of the other, of the other [...] you could be going through that situation [...]. (N7)

[…]. A sadness [...] for the parents [...] when a loss happens. [...]. That issue of expectation, planning, going home, not having the child, [...] gives me a huge sadness [...], it is very sad, painful [...]. (N10)

As nurses, we are sad because we don't want to lose the patient, we don't want to lose the baby, we always try our best, not to [...] this happens, because our happiness is when a child goes home well, home with his father and mother [...]. (N12)

[...] It is of impotence [...] for me [...] the main emotion like this [...] is a feeling of frustration [...]. (NT21)

[...] You are powerless and cannot do anything as a professional, sometimes the baby has nothing else to do and you are powerless in that situation [...]. (NT22)

The speeches also highlighted the suffering of professionals, such as that of one of the participants, who mentioned that she felt "terrible" when seeing a family losing a child and catching him dead for the first time. This greater suffering is mainly due to the bond built with the baby and/or the family, often due to the long period of hospitalization.

For me it is a great suffering to see a family lose a child [...]. To pick up a dead child for the first time is very sad [...]. I remember feeling terrible [...]. (N1)

[...] Sometimes we have stronger bonds with some mothers, consequently, the experience of bereavement also depends a lot on that, sometimes we are very involved with that family, and we feel it, it hurts us [...]. (N10)

[…] We accompany them [...] sometimes for up to two, three months, we can't not create a bond, [...] I suffer with them [...]. (NT13)

On the other hand, bereavement for a child who was unlikely to survive (cited as examples: extreme premature, extreme low weight and/or with malformation and that, thus, the participants mentioned as a presumed death), is easier to elaborate and causes less suffering for the professionals. However, even so, for the parents, the loss remains as a shock, which occurs, as an example, when this newborn, for whom there was no expectation that he/she would be born (or survive birth), is born and survives for a few hours or days, in this way, the acceptance of the loss becomes more difficult for the parents, as they create a bond with their child, and is, therefore, also a moment of difficulty for the professionals that accompany them.

*[…] When the child is not viable, [...] very low weight, extremely premature [...], you already understand that maybe it will not be able to [...] survive, but the one that is born beautiful [...], healthy, with good weight, strong, and then it is discovered that it is cardiac, for example [...], it is very difficult to accompany at the time of loss [...]. (*N7)

[...] It was a baby badly formed, it was a death that would happen, that had no compatibility with life, but it was very difficult, because you see the suffering, especially the mothers, because she [...] had gone through the whole pregnancy [...]. She always has the hope that that baby will live [...]. It ends up that the child died [...], even if it has a malformation, that it will die, the acceptance is much more difficult [...]. (N11)

The participants reported that, although it is difficult, and they are often shaken

when they go through bereavement situations with their parents, as time goes by, they feel more prepared and are able to deal with these situations better. Therefore, it is understood that this contributes to face the bereavement experience and to develop "protection and defense mechanisms" to avoid suffering so much with these situations.

[...] Now I know how to deal better [...]. I try not to take this feeling too far [...]. That situation is over, I try to forget it so that it doesn't stay inside me. (N5)

[...] With time we learn to protect ourselves too, not that we don't suffer, [...] we create protection mechanisms, so that we don't get shaken. The first time was very difficult, I shook myself [...], but then [...] you protect yourself. (N16)

In the category "Experiencing nursing care in the face of parental bereavement", it was observed that some professionals prefer not to get emotionally involved, try not to talk to parents about what happened, avoid the situation, try not to know the family's story and are not present at the time of the news of the death, which is considered unpleasant. What can demonstrate situations of "escape" when dealing with the death of the newborn and the parents' bereavement.

When the baby dies, my wish is not to talk to the mother anymore, not to see her anymore, not to be the unpleasant one to say that the baby passed away. (N1)

[...] I avoid, sometimes even knowing too much of the story, going into details [...], not getting involved and not having so many feelings related to this [...]. So, it is better for you to stay more distant [...], we can't bring this feeling to us [...]. (N11)

As for nursing care in the face of parental bereavement, strategies based on empathy, welcoming and sensitive listening were mentioned, with emphasis on not minimizing the parents' pain and bereavement.

[..] Never minimize the mother's pain, never, regardless of whether this baby was desired [...], never underestimate this pain [...]. (N2)

[...] Listen to the person, be sensitive, the person will express his pain, his anger, his crying [...], so we must be very sensitive, careful with the words, because only who knows is who experiences this situation [...] (N15)

[...] Respect the father's moment, if he wants to be hugged, to be welcomed this way [...] or if he wants to remain silent [...]. There are fathers that will want to talk to you, that will want to express their feelings, we must know how to listen [...] (N16)

[...] In the situation that they [parents] are living, have patience, tolerance, [...] empathy. (N19)

[...] The most important is comfort, either with a hug, and depending on the situation [...] you can even talk. I think you can even talk, but [...] you must be very careful what you say, [...] you must respect that moment. (NT9)

In addition, "being present", "being close" and "being together" were expressions that appeared in the reports, demonstrating the availability to be by the parents' side, providing welcoming and support.

[...] of us being present at that moment, being close [...]. (N4)

[...]We can only say that we are there, and that we are together. (N7)

[...] make yourself available, say that you are there, you are present, you know that they are suffering, [...], that you are participating in that suffering with them, they are not alone [...]. (N19)

The reports showed that professionals seek to respect the privacy of parents, allowing them to be at ease, which can be provided with the use of screens, thus favoring a more restricted place to have their moment of farewell.

[...] We must take great care is privacy, the whole team knows that there is a child dying, but the other mothers also know [...] there is a monitor that does not have the same numbers as the others [...], father and mother cry [...], we put up a screen [...] (N1)

[...] I try to respect as much as possible the privacy of the parents in this moment [...]. Allow them to do what they really feel comfortable doing [...] (N10)

[…] Leave them in a more restricted environment, put them behind screens [...] to have that moment with them, of farewell. (N4)

The participants emphasized that they try to meet the parents' wishes, offering and allowing the family to touch and hold the lifeless baby, if they want to.

[...] I try to leave the family at ease, to [...] take the child in the lap, to say goodbye [...], to have a moment there, theirs. (N5)

[...] ask if he wants to take the child in my lap, because it will be the farewell to that child, then it depends on each reaction of these parents, some will want to, others won't [...], but my reaction depends a lot on the reaction of the parents [...]. (N16)

They also reported cases in which the parents' wish for the baby to be baptized before death was fulfilled. Still, the professional met the request of a mother who wished to have her picture taken with her dead son.

[..] I remember cases in which the parents asked that the baby be baptized before death, trying to do what they wanted (N1)

[…] The mother asked me to take a picture of them, the father, the mother with the baby [...]. She had already lost six babies, that was the seventh that was going to die, the others were not born, she asked me because she wanted a picture of the family, it was a very sad picture, but one that meant a lot to her, it was now during the pandemic, they were wearing masks, and I told them: take off your mask for the picture. (N1)

In the category "Knowledge and beliefs about the experience of parental bereavement", it was possible to address the sources of strength to cope with parental bereavement, namely personal beliefs, and knowledge about the topic. Most participants reported that the knowledge acquired about parental bereavement came from their own professional practice and personal life experiences when suffering the loss of family members.

[…] It comes a lot from the experience that I had and that I've been through here, not only in Neo [...], but we also end up taking a little from our personal experience [...]. (N5).

[...] I think that knowledge comes from our experience, both personal and professional, we have been in this profession for 17 years, so we have dealt with many situations of bereavement [...]. (N16)

My knowledge comes from the experiences over all these years that I work in Neo [...]. (NT17)

They also mentioned the importance of addressing the theme in continuing education activities, mainly mediated by psychology.

We received many lectures, especially with psychologists, to know how to deal with this bereavement, so that was where I had the most experience and learning. (N2)

We had a psychologist [...], she brought us some approaches about bereavement, and one of the things I learned with her, is that the father has that idea of the baby [...] perfect [...], of the baby being born and taking it home, so the bereavement is not only the loss of the baby, right there [...], it comes from a whole pregnancy [...]. (NT17)

Some reports bring, as a strategy for coping with bereavement, religiosity, encouraging positive thoughts and words of strength based on faith and the belief in the existence of a God.

[...] Encourage positive thoughts, and they often have religious beliefs, so this is also a strategy that we end up using a lot [...]. (N6)

[…] For those who believe in God, that each one has a time of life here, so in a little while that child [...] came to bring a message to the parents, to the family, so I think that [...] nursing is to give the best of oneself, but knowing that we are impotent before God [...]. (N7)

[...] Each one has his faith, his heritage [...], from his experience, and we also bring this to our professional life, and we as human beings cannot help but sympathize with the other who is there suffering [...]. (NT13)

DISCUSSION

Regarding the results, the feelings of sadness and impotence stood out, which are in line with research[10] that evidenced that the action of accompanying the process of death and dying of children, as well as the parents' bereavement, provoked in the professionals' feelings of anguish, impotence, and sadness. In this difficult moment, nurses feel frustrated and impotent for not being able to help even more. This leads these professionals to assume a distant posture, as well as preferring not to get fully involved in these situations[10].

As far as professionals are concerned, when facing the death of children who are under their care, they are often taken by feelings related to the involvement with death, such as sadness, which prevents them from continuing their work activities during the rest of the day. Therefore, it is becoming common for nursing professionals, when living with the loss in their daily lives, to seek separation currently, to naturalize this process of extreme anguish[11].

Another point worth mentioning is the statements about bereavement for a child whose survival is not very viable. In a similar Brazilian study, nurses reported similar reflections about life, death, and survival of NB with severe complications[12]. Regarding the loss of a NB that went to the NICU due to premature or malformed birth, or that had complications during labor/partum/postpartum or even by a fatality, the team must be aware that, regardless of what happened to this NB, the parents went to the maternity ward to give life for their child, and that, as often happens, although it was the result of a healthy pregnancy and prenatal, they left the hospital with empty arms[13]. Therefore, it is important to reflect on the statements of the participants in this research, who highlighted the relevance of the period of care practice to feel prepared to face the situation.

An international systematic review highlights that when the newborn dies in a NICU, parents experience events in a different environment from other types of bereavement, such as the death of a partner. Certain aspects of death in a NICU are intrinsic to this context, and the experiences are different from other forms of bereavement. It is also an adverse context in relation to parents who experience anticipated perinatal losses, as the bereaved at a NICU have a moment prior to death, in which there is involvement with their child as a live birth[14].

As for the approach to the patient and his family, the psychosocial support and the help for relief and physical well-being can be worked on during the academic training through simulation, enriching the clinical practice of nurses in this perception[15].

When dealing with bereaved parents, some of the professionals' attitudes stand out: empathy, welcoming, and sensitive listening. In another international study[16], nurses offer considerable support to families by being with them during this process and even beyond.

Considering the need for humanization, perception, and applicability of holistic observation by health professionals for individuals experiencing bereavement, the discussion is based on the understanding of bereavement as a process that permeates physical death, permeating the loss of bonds[17]. Thus, nurses should focus on the family members, using therapeutic communication skills in the process of death of neonates. It is also important to stimulate the participative dialogue according to the parents' needs, and the nurse must value the bond between the health service and the bereaved family members[3].

In view of the above, the visibility of the patient is considered, directed to the bio-psycho-socio-spiritual aspects. This is because health care is not only linked to the simple fact of assisting within a perspective of action centered on doing, procedures, and techniques, but also to the issue of seeing patients and their families as unique human beings, living with them this difficult moment in their lives[10].

The reports also show that the nursing team respects the privacy of the parents at the time of the loss of their child. In this context, it is possible to humanize the assistance to the loss, individualizing the care, mobilizing organizational and physical resources of the institution itself, without, however, the need for large financial investments. Thus, it is possible to provide an adequate physical environment, creating a scenario of privacy for the proper individualized welcoming of the family that is experiencing this moment[13].

In the face of the event of loss, professionals seek to ensure the well-being, dignity, and respect for the parents and the body of the NB, even if lifeless, demonstrating attitudes that value humanization and appreciation of patients[13]. Thus, considering that the welcoming and the ambiance are one of the concepts guided by the National Humanization Policy (PNH)[6], health professionals who have technical and scientific competence to develop them tend to be better prepared to deal with situations of loss, knowing that this moment will be remembered by parents and family members for their entire lives[11].

Corroborating the findings of this study, the initiatives of placing the baby's body on the parents' lap, allowing them to take pictures with the lifeless child, among others, are in line with other reports[13], which state that gestures such as these are important at any time of loss. Regardless of the parents' manifest desire to have contact with their child, it is essential to offer these initiatives, as they provide comfort through memories and affective memories[13].

In this sense, another international qualitative research with Jordanian nurses highlighted the importance of implementing a continuing education program for nursing professionals because, according to the participants, during their graduation, they were not prepared to face bereavement in their daily professional life[19]. Thus, the professional qualification becomes positive to develop humanized care, since it provides opportunities for debates on the subject, aiming to combine technique, competencies, and skills of dialogue and integral care in a comfortable and safe work environment. This ensures improved quality for the patients and their families in this difficult time[17].

It is mentioned that spiritual practices and their beliefs often help professionals, patients and/or families, who, linked to this, rebuild the meaning of life when facing the pain of loss[15]. In an international study, spirituality was pointed out as important in the daily routine of nurses, being a significant element in coping with bereavement soon after the loss of a patient[18]. It is pointed out that religious or spiritual support during bereavement is a strategy used to face the period experienced to provide inner encouragement, relief,

and comfort[15].

One of the studies also cited faith and spiritual beliefs as coping strategies for bereavement. In addition, nurses state that the professional experience over the years helps in this coping process, making them know how to deal with pain and suffering when facing bereavement[19], which converges with the results presented here.

It is understood that the study was limited to the reality of a NICU of a public hospital. Therefore, a more sensitive look is suggested for future research on this topic, leaving, as a suggestion, practical interventions aimed at permanent education in services directed at nursing actions in the face of parental bereavement.

CONCLUSION

When getting to know the experience of the nursing team in a situation of parental bereavement, they highlighted sadness, helplessness and suffering as the main feelings. As for the professionals' performance and care in the face of this bereavement, we identified, besides some "escape" strategies, several strategies based on empathy and humanization, such as welcoming, privacy, sensitive listening, and availability to meet the wishes of bereaved parents.

Regarding the knowledge and beliefs about parental bereavement, the professionals' sources of strength to cope with this moment, in general, come from personal beliefs and from the knowledge that comes from their own experiences of loss in their personal and family lives, as well as from their professional experience over the years. In addition, the study pointed out that religiosity is a strong strategy for coping with bereavement for both parents and nursing professionals.

As for the implications for the care practice, the need for more moments of permanent education on the theme stands out. This was pointed out by the team, who suggested continuing education activities, especially with the mediation of psychology, which could contribute to the acquisition of knowledge for coping when experiencing situations of parental bereavement.

It is believed that the results of this study will serve as a subsidy to guide health care assistance to bereaved parents, and that it will also contribute to promote reflections by health care professionals regarding the essential skills to care for parents who are experiencing the process of death of a child and bereavement.

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Corresponding author:
Luciana de Carvalho Pires
Universidade Franciscana (UFN)
Rua dos Andradas 1614 , Bairro Centro, Santa Maria , RS, CEP 97010030
E-mail: lucianadepires@hotmail.com

Role of Authors:
Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **Pires L de C, Costenaro RGS, Gehlen MH, Pereira LA, Hausen CF, Neves ET**; Drafting the work or revising it critically for important intellectual content - **Pires L de C, Costenaro RGS, Hausen CF, Neves ET**; Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **Pires L de C, Costenaro RGS, Hausen CF, Neves ET**. All authors approved the final version of the text.

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